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Patients Attitude to Technology

A way to improve hydrocephalus management and follow up using smartphone intelligent application

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Abstract Smartphone applications ("apps") have become ubiquitous with the advent of smartphones and tablets in recent years. Increasingly the utility of these apps is being explored in healthcare delivery. Hydrocephalus is a condition that is usually followed by a neurosurgeon for the patient's life. We explore patient acceptability of a mobile app as an adjunct to outpatient follow-up of patients with hydrocephalus. A questionnaire was circulated amongst patients with hydrocephalus (adults and children). Patients were asked questions about their hydrocephalus; expectations for outpatient follow up, whether they have smartphone/tablet/internet access and whether they would be interested in a mobile app for their long term hydrocephalus follow up. 191 patients completed questionnaires, 154 of these were completed online and 37 in paper form. 98 respondents were adults (mean age 46) and 93 were children less than 18 years old (mean age 8). Overall 36.1% of patients did not know the cause of their hydrocephalus. 96.7% have a shunt. 76.5% of adults and 80.6% of children had 1-4 shunt surgeries, 14.3% of adults and 11.8% of children had 5-9 shunt surgeries, 3.1% of adults and 5.4% of children had 10-14 shunt surgeries. 71.7% of patients expect to be followed-up routinely in clinic for life. All children had smartphones or tablets, compared to 86.7% of adults. Children were more interested in a hydrocephalus app, 84.9% saying yes, compared to 71.4% of adults. Adults who were not interested in the app did not have a smartphone or tablet. Hydrocephalus management is a lifelong task and innovations in technology for engaging patients in its management are vital. The majority of patients are interested in mobile apps for outpatient management of hydrocephalus. We will follow this up with a feasibility study of a custom designed hydrocephalus app.

Keywords Hydrocephalus · Follow up · Intelligent approach · Smartphone apps

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1 Introduction

Hydrocephalus is variably described as an enlargement of ventricular system of the brain resulting from inadequate passage of cerebrospinal fluid (CSF) from where it is produced within the cerebral ventricles to its point of absorption into the systemic circulation [1], the incidence in high-income countries is approximately 79 per 100,000 births [2]. Treatment of hydrocephalus depends on the aetiology, with ventriculoperitoneal shunt (VPS) being the commonest intervention (up to 3500 performed per year in the UK alone [3]). Endoscopic third Ventriculostomy [4] and choroid plexus coagulation [5] are less frequently used treatments. Hydrocephalus is generally considered as a condition that requires lifelong management. In long-term follow-up series of adults with paediatric-onset hydrocephalus, up to 89% of patients still possess an implanted shunt [5]. It is commonly advised that adults with hydrocephalus who remain shunt dependent should be regularly followed to help manage and avoid potential complications associated with chronic shunting [5].

Headaches are a common complaint amongst patients with a diagnosis of hydrocephalus even when adequately treated, with 10-20% of children reporting severe headache [6]. Serious chronic headaches are seen in approximately 40% of adults with shunted hydrocephalus [7]. Finding new ways to engage patients with their healthcare is essential. Mobile healthcare ("m health") applications ("apps") are software programs that run on internet enabled devices like smartphones. Their potential for use in wide range of medical and health related issues is increasingly being explored [8]. The "Hydroapp", developed with John Moores University in Liverpool is a web-based management, administration, communication and m-health application that provides follow-up treatment for patients with hydrocephalus or chronic headache. Patients will record all the pain events and the episodes related to those events, as well as a quick way to fill-in diaries, outcome measures and health questionnaires.

2 Methods

A questionnaire was circulated in an electronic form via a google forms through the patient group Shine[1] (Spina bifida • Hydrocephalus • Information • Networking • Equality) and in a paper form in neurosurgical outpatient department in the Walton Centre, Liverpool. Parents were asked to complete questionnaires on behalf of children with hydrocephalus. The questionnaire included 33 questions in 2 parts; Part 1 asked participants about their hydrocephalus, aetiology, number of shunt operations, outpatient follow-up experience, and accessing emergency or urgent help. Part 2 explored participant access to internet/smartphone technology, opinions about using technology to manage living with your shunt and how important or relevant certain potential features of a hydrocephalus app would be to them.

3 Results

191 patients completed questionnaires, 154 of these were completed online and 37 in paper form. As shown in table 1, about 80% of these were completed online and the rest in paper form. 51.3% of respondents were adults (mean age 46.1, range 18-83 years) and 48.7% were children less than 18 years old (mean age 8, range 0-17 years).

3.1 Aetiology of hydrocephalus

Overall 36.1% of patients did not know the cause of their hydrocephalus. Of the 98 adults, 29 had normal pressure hydrocephalus (NPH), 29 did not know the aetiology of their hydrocephalus, 18 had tumour related hydrocephalus, 7 had Idiopathic Intracranial Hypertension(IIH), 7 had post haemorrhagic hydrocephalus, 5 had post infection hydrocephalus and 3 had spina bifida associated hydrocephalus. Within the paediatric group, 40 of the 93 respondents did not know the cause of their hydrocephalus. 22 had post haemorrhagic hydrocephalus, 9 had NPH, 8 had post infection hydrocephalus, 8 had spina bifida associated hydrocephalus, and 5 had tumour related hydrocephalus. No child had IIH, compared to 7.1% of adults.

[1] https://www.shinecharity.org.uk/

Table 1 Participants in this study

Data collection method	**Adult**	**Children**	Total
Online	83	71	154
Paper	15	22	37
Total	98	93	191

3.2 Shunts

Overall 97% have a shunt, 95.9% of adults and 97.8% of children currently have a shunt. 76.5% of adults and 80.6% of children had 1-4 shunt surgeries, 14.3% of adults and 11.8% of children had 5-9 shunt surgeries, 3.1% of adults and 5.4% of children had 10-14 shunt surgeries. Non of children had more than 15 surgeries, compared to 3.1% of adults who had 15-19 surgeries.

3.3 Waiting time

About 42% of all patients had to wait between 16 and 30 minutes to be seen by specialists, while 5.7% of all patients had to wait up to 60 minutes. About half of the patients spent 10-15 minutes with doctor or nurse in the clinic. 36.7% of adults and 25.8% of children spent more than 15 minutes in clinic.

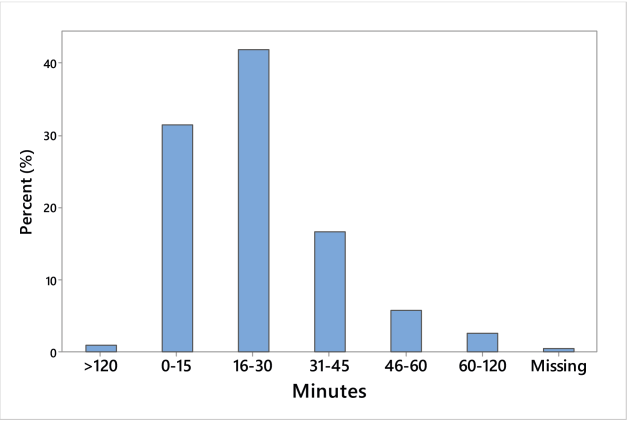

Fig. 1 Waiting time at the clinic

3.4 Patients' expectations for follow up

Patient preference for how they would like to be followed up can be seen in figure 2. The majority of patients, both adult and children, would like to be seen by the neurosurgery team in clinic every 6 months or yearly. 20% of adults prefer to be seen in clinic only when they have problems. Overall, 71% of patients were expected to be followed-up routinely in clinic for life. The commonest long-term concern for these patients is blockage/shunt failure/malfunction (66/98 adults, 72/93 children) followed by infection (13/98 adults, 16/93 children).

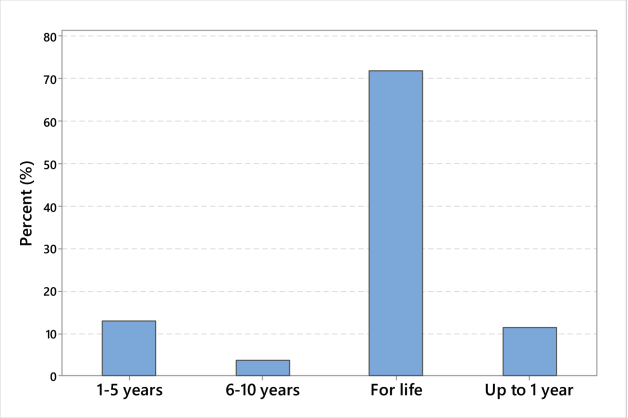

Fig. 2 Patients' expectations for follow up

3.5 Access to internet/smartphone

The majority of patients have a home computer with internet access (95% of adults and 90% of children). All children had smartphones or tablets, compared to 87% of adults. Type of smartphone was evenly split between Android and Apple iPhone. 44.9% of adults and 43% of children owning Android smartphone versus 40.8% of adults and 53.8% of children owning an Apple iPhone.

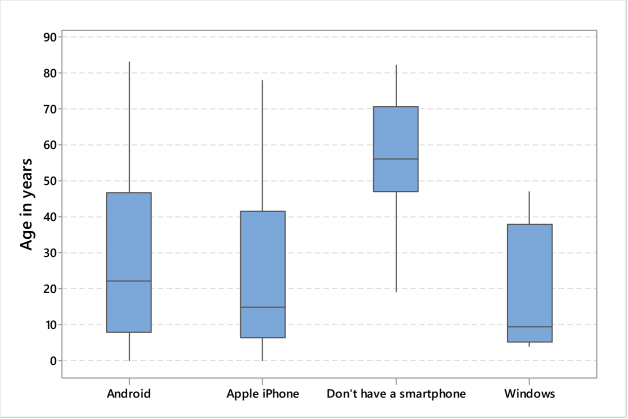

Fig. 3 Type of smartphone

3.6 Interest in a hydrocephalus app

Children were more interested in a hydrocephalus app, 84.9% saying yes, compared to 71.4% of adults. Adults who were not interested in using hydrocephalus app (mean age 56.5 years) didn't have a smartphone or tablet as shown in figure 3.

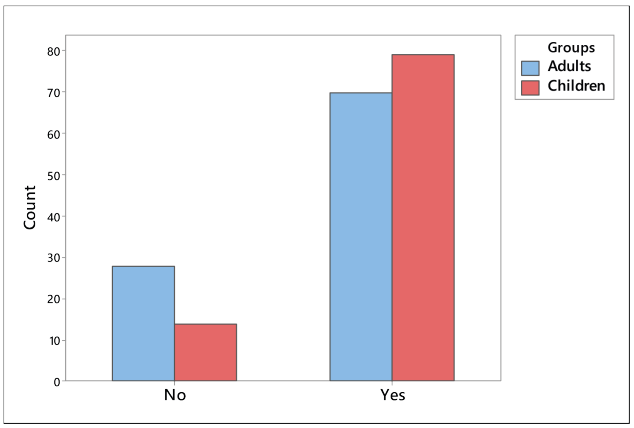

Fig. 4 Patients' interest in using technology for follow up

Of those who were interesting in using Hydroapp for long-term follow up, most cited multiple reasons shown in table 2 as very or extremely important on a scale of 1 to 5 (i.e. from least important to most important). Recording details about their shunt was the most commonly cited reason for interest in an app for adults (78% of adult respondents, though 96% of children also), whilst in children it was to alert the treating team in 95%. It is obvious that recording headache score, general health, and alerting medical team, were also seen by patients as important aspects in term of using Hydroapp for self-management and follow-up. However, making video-call in general was the lesser important aspect from patients point of view.

Table 2 Important aspects of using Hydroapp for follow-up

	Adult	**Children**
Record headache score	70%	77%
Record general health and well-being	68%	84%
Alert treating team	86%	95%
Record/update details of your shunt	78%	96%
Video-call appointment	56%	52%
Emergency consultation using video-call	65%	68%

4 Discussion

According to the Office for National Statistics the percentage of adult internet users has increased from 80% in 2011, when comparable records began, to 89% 2017. Virtually all adults aged 16 to 34 years were recent internet users according to the Office for National Statistics [2]. In 2017, 76% of UK consumers owned a smartphone, up 5% year on year. Laptops were the second most commonly-owned internet enabled device in households (64%), followed by tablets (58%) [9]. Mobile apps are increasingly being used for more than just social networking and entertainment with 80% of users aged 18-24 using at least one finance app and almost two-thirds of users aged 18-24 using a fitness app [9].

There has been an explosion of mobile healthcare applications in tandem with the expansion of internet access and smartphone ownership. 325,000 health apps (health, fitness and medical apps) were available on all major app stores as of 2017. $5.4 billion have been invested in digital health in 2016 alone [10]. Text message interventions via mobile phone are widely reported in conditions like in diabetes [11]-[15] and in smoking cessation programmes [16]-[21]. Smartphone apps have been used to allow physicians to monitor patients with chronic heart failure [22] and in diabetes education [23]. Like with diabetes, the application of "m health" is a promising adjunct to clinical care as it addresses the demand for ongoing support in the management of chronic conditions.

There is an obvious enthusiasm for developing m health apps but there are challenges to adopting this technology. A study in 2015 showed two-thirds of apps within the NHS health apps library [24], a pilot programme which list NHS approved healthcare related mobile apps, sent identifying information over the internet and did not use encryption. Developing an app that will transmit patient identifiable information requires adherence to the major governing legislation (in the UK this is the Data Protection Act 1998 [25]) and as such needs to be developed with due diligence.

The Hydroapp is being developed with John Moores University in Liverpool, in accordance with the requirements of hydrocephalus specialists at Alder Hey Children's NHS foundation trust and Walton centre, Liverpool. The central database and server application will be hosted on AIMES[3] data centre, which meets the NHS criteria for information security and governance and currently hosting data for The Institute of Child Health and Liverpool Heart and Chest Hospital. The central database of Hydroapp will store anonymised data. Patient profiles will have no name or personal details that may expose their identity. Collected data from patients' smartphones will be saved in numeric format rather than plain text. The numeric representation of data will not provide any details about patients, only the server app can display this representation into understandable format. Moreover, numeric representation requires much less storage space and query time.

Hydroapp includes a range of patients self-reported outcome measure and monitoring forms such as hydrocephalus outcome questioner (Hydro-OQ), EQ5D-Y and EQ5D-3L, headache impact test (HIT6), headache diary and visiting reports. Using Hydroapp as a follow-up technique and data collection method will ensure that economic and patient-reported outcomes are recorded efficiently. It will be assumed that the standard use of such smartphone based PRO (patient reported outcome) and intelligent software will be able to reduce unnecessary visits to neuroscience centres, whilst enabling and improving communication between patient and neurosurgical care and follow by creating appropriate clinical thresholds for alerting medical staff of changes in symptoms or of changes of behaviours and of symptoms automatically. Thus, it is improving safety whilst reducing unnecessary costs and speeding up communications and access when it counts.

Hydroapp improves monitoring of historical responses to therapies and recording of side effects. This platform provides an on-the-go analysis of a patient's data, which improves doctor's productivity and decision-making. The accumulation of data and doctors' experience will be stored in a knowledge base, which enables Hydroapp to train itself allowing knowledge to be expressed and bounded to identifying risk and alert healthcare provider. The use of intelligent methods within Hydroapp can improve healthcare delivery by allowing a proactive resolution such as identifying risk level of certain cases, and then automatically prioritise alerts and waiting list. Without such intelligent solution, too many hours can be spent analysing pain events to reveal meaningful patterns, whereas identifying risk in early stage helps specialists to take action before serious complication occurs. Hydroapp with support of artificial intelligence can absorb thousands of patients' records and make sense of them instantaneously. Hydroapp automates all the heavy lifting of analysis and discovery that take teams of medical experts hours or days, artificial intelligence does on the fly to proactively identify problems and pinpoint the underlying root cause. Such application enabled by data science and advanced intelligent methods would convey revolutionary impacts in the healthcare domain.

The market penetration of internet access and smartphone usage means that the vast majority of our patients have the potential to engage with smartphone apps in their daily lives. Our survey shows that there is an appetite amongst our patients to engage with healthcare in new ways and with new technologies. We are facing an increasing need to balance patient expectations with the resources available in a modern NHS. We have shown that patients expect to be

[2] https://www.ons.gov.uk/

[3] http://www.aimes.uk/

followed by their neurosurgery team for life when they have a shunt. Patients are understandably concerned about the potential for shunt malfunction/infection and wish to maintain contact with the treating team. These concerns are mirrored by neurosurgeons who fear missing a potential shunt malfunction which is potentially a life-changing/life-threatening event.

The reality is that the vast majority of routine outpatient appointments for hydrocephalus do not uncover new symptoms that require neurosurgical attention. The patient +/- their family take time out of school/work and travel, often significant distances, to attend clinic. Outpatient clinics are very regularly at capacity or overbooked and the time and resources spent on these routine interactions could well be better utilised. When a problem with a shunt does arise, patients commonly present to their GPs or their local hospital, which can lead to delays in accessing neurosurgical advice and care. We propose that following these patients with a hydrocephalus app could facilitate a more efficient patient-healthcare interaction with proactively responds to changing symptoms. Thus a technology such as this should be a perfect vehicle to maintain surveillance of a potentially catastrophic event like shunt malfunction without overburdening a health service with regular face to face contacts in the outpatients.

5 Conclusion

Hydrocephalus essentially constitutes a lifelong disease with brief episodes where patients need actual neurosurgical input. Innovations in technology for engaging patients in its management are vital. In this study, we have found that the majority of patients are interested in mobile apps for outpatient management of hydrocephalus. In response to our survey, we have developed Hydroapp with support of patients volunteer and foucusing on the patients expectations as per table 2. We will follow this up with a feasibility study of the custom designed Hydroapp.

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